Reference of the paper.

Winance, M., A. Damamme and E. Fillion (2015). "Thinking the aid and care relationship from the standpoint of disability: stakes and ambiguities." ALTER - European Journal of Disability Research / Revue Européenne de Recherche sur le Handicap 9(3): 163-168.

Editorial

THINKING THE AID AND CARE RELATIONSHIP FROM THE STANDPOINT OF DISABILITY: STAKES AND AMBIGUITIES

PENSER LA RELATION DÔAIDE ET DE SOIN A PARTIR DU HANDICAP ENJEUX ET AMBIVALENCES.

M. Winance [a b c d], A. Damamme [e f], E. Fillion [g h]

[a] INSERM, U988, Villejuif, F-94801, France;
[b] CNRS, UMR 8211, Villejuif, F-94801, France;
[c] EHESS, CERMES3, Villejuif, F-94801, France;
[d] Université Paris-V, CERMES3, Villejuif, F-94801, France;
[e] Université Paris VIII, CRESPPA-GTM, Saint-Denis, F- 93526, France;
[f] CNRS, UMR 7217, Saint-Denis, F- 93526, France;
[g] EHESP, CRAPE, Paris, F-75013, France ;
[h] Maison des Sciences Sociales du Handicap, Paris, F-75013, France ;

Adresses e-mail :
winance@vjf.cnrs.fr
fillion@vjf.cnrs.fr
adamamme@yahoo.fr

Authors document

Editorial

THINKING THE AID AND CARE RELATIONSHIP FROM THE STANDPOINT OF DISABILITY: STAKES AND AMBIGUITIES

For approximately thirty years in Anglo-Saxon countries (Gilligan, 1982; Tronto, 1993) and more recently in France (Garrau & Le Goff, 2012; Molinier, 2013; Paperman, 2013; Paperman & Laugier, 2006) a school of the social sciences, called the *ethics of care*, has criticized the ideað carried by progressive thought since the Enlightenmentð of a rational, autonomous, individual subject (the modern, Cartesian, Western subject). Indeed, for these authors, vulnerability and dependency are constitutive aspects of everyone, no matter who, and bring about a need for care. More specifically, these dependency relationships, viewed positively, have been analyzed as being at the source of a unique moral experience (Gilligan, 1982)ð care, defined as attention to others, concern for their well-being and concrete activities targeting this well-being.

Use of the word *ethics* references this moral potential in dependency relationships: preserving these constitutive relationships for human beings, through care, is a moral stake on equal footing with the quest for justice. Hence the goal of this school of thoughtð to rehabilitate the practices and values linked to care, which are often hidden, implicit, or even denigrated. First focused on women and the ñmother-childò relationship, thinking about them was careful to differentiate itself from a type of essentialism that others had ascribed to it and that claimed that women were ñnaturallyò inclined to provide care to ñnaturallyò weak beings (children, the ill, the elderly or disabled, etc.). Several authors called attention to this assigning of care work to certain social groups based on oneôs belonging to a gender, class

and race (Glenn, 2009; Tronto, 1993). These authors showed that while care relationships are first interpersonal, they are also caught in a historical process and a broader social context. They analyzed how care dovetails and is defined across different levels: direct care relationships (micro level) and the social or institutional coverage of care needs (macro level), and by so doing invited questions about the borders between the private and the public spheres. Thus, the ethics of care, from the ñstandpoint of dependencyò (E. F. Kittay, 1999), promotes a new figureð the person and citizen, fundamentally relational, that is elaborated and evolves by and in care relationships; it also emphasizes imbalance and the emotional dimension of this care relationship.

This school of thought encountered research on disability, but ran intoð sometimes radicalð criticism, notably from another school of thought that had grown out of the mobilization of disabled people: *disability studies* (Albrecht, Ravaud, & Stiker, 2001; Albrecht, Seelman, & Bury, 2001; Barnes, 1999; Longmore, 1985; Oliver, 1990).

Indeed, disability studies were developed on the basis of a protest against existing practices, notably those relating to the medicalization and institutionalization (and more particularly in the context of re-education and rehabilitation) of disabled persons, which were experienced as infantilizing, oppressive and segregating. In the 1970s, people with disabilities thus became involved in a collective protest movement (Anspach, 1979; Shakespeare, 1993; Zola, 1989). They reformulated their experience as one of ñbeing excluded by societyò and no longer as one of ñindividualsô maladjustment to society.ò They then defined disability as a social construct, a consequence of architectural, economic, legal and cultural barriers that society imposes on people with disabilities, rejecting the vision that had prevailed until then in which disability was the result of an individualôs biological and/or psychological deficiency.

It was in this way that the now known opposition between two models of disabilityð the medical model and the social modelð was formulated. Building on a negative and

pejorative vision of dependency, disability studies have on the contrary asserted the capacity of people with disabilities to decide for and by themselves and control their lives (ñNothing about us without us.ò). In so doing, they criticized the normative nature of the able-bodied (that is to say the bio-functional standard that constitutes them), while promoting the idea of an autonomous subject that is the only one capable of defining and evaluating the services he or she wishes to receive and who must be able control them without being caught in emotional ties with the care provider (or ñcarerò). This demandð autonomyð associated with a denunciation of the domination relationships undergone until then in care practices was at the heart of the movementôs fight. This initially lead disability studies to reject the relevance of care thinking, and even to denounce it as a continuation of an ideology of dominating people with disabilities, who were perpetually portrayed as materially and emotionally dependent and passive (Fine & Glendinning, 2005; Keith, 1992; Morris, 1997; Silvers, 1995). In order to emphasize the determination of people with disabilities to have control and autonomy in their daily lives, these authors defended the implementation of a formalized and functional aid relationship of a contractual nature without any emotional dimensions. They used terms such as ñ*help***ò**, ñ*support***ò** and ñ*personal assistance***ò** to oppose the idea of care (Finkelstein, 1998; Shakespeare, 2000).

The divergences between these two schools of thought are anchored in the political and scientific history of each and derive notably from the viewpoint each adopted. The ethics of care analyzed care by insisting on the position of the carer and the capacities and values that the carer developed in the care relationship; disability studies, for their part, insisted on the position of the person receiving the care and on the subjugation to which the care relationship could lead. These divergences lead both schools to different concepts of the individual (dependent versus autonomous), of the nature of the relationships between people and making up society (relationships of interdependency versus relationships between

ñautonomousò individuals) and therefore also of dependency (a jointly shared situation versus a subjugating situation to ban), etc.

However, beyond these divergences, these two schools shared a starting pointð criticism of how care was organizedð and a goalð the emancipation and transformation of the status of the people concerned, whether providers or receivers of care. Thus, progressively, these two schools of thought deepened and developed critical feedback on their own stances. Some authors entered into a dialogue, re-examining thinking on care from the standpoint of disability or the inverse (Beckett, 2007; Hughes, Mckie, Hopkins, & Watson, 2005; Kröger, 2009; Silvers, 1995; Watson, Mckie, Hughes, Hopkins, & Gregory, 2004; Williams, 2001). Beyond approaching care in terms of needs to meet, and receivers and providers, research on care insisted more and more on the notion of interdependency and relational autonomy (Mackenzie & Stoljar, 2000). Eva Kittay (E. Kittay & Feder, 2002), a never-before published article by whom is presented in this issue, has shown that asymmetrical relationships are not necessarily relationships of domination, that care relationships are not unequivocal and that the positions of provider and receiver are not always assigned. In the field of disability studies, new generations have criticized the radical nature of the social definition of disability that completely ignored the experience of the body and disability and the intimate and private dimension of disability, and wanted to produce a less abstract vision of disabled people (Morris, 1991; Shakespeare, 2006; Thomas, 1999). Finally, other schools, such as the sociology of technology (Mol, Moser, & Pols, 2010; Pols, 2004), have taken up the question of care, giving rise to a diversity of approaches that, beyond the initial feminist approach, combine the contributions of these different schools of thought.

The two special issues of the journal *Alter* on the topic of ñcare and disabilityò aim to extend the debate and dialogue begun between these different schools of thought on the nature of the aid relationship, its effects on the description and definition of people (aid providers

and aid receivers), and on the inherent ambiguities and tensions. These issues are the outcome of a call for articles that circulated in different institutional and national arenas across disciplinary divides, and were a great success. Thirteen articles[1] will be published in these two issues.

In this first issue, we have assembled, around a submission by Eva F. Kittay, accompanied by a commentary by Marie Garrau, articles that discuss the issue of the care relationship ñin daily life.ò They look more specifically at the identity of care providers (women or men, spouses or fathers, brothers or sisters, family and friends or professionals), the nature of the relationship that grows between care providers and the people they aid and that sometimes extends over long periods of time. The care relationship covered here makes it possible to examine how people, their positions, their respective roles and their capacities can, in return, be redefined and redescribed. Analyzing concrete care situations and revealing the ambiguities in the relationships at work, each article examines in its own way the limits of both the ethics of care and disability studies.

The first article is that of E. Kittay. In this text, the author questions the link between the notion of normality and the definition of what constitutes a good life. Anchoring her philosophic reflections in her personal experienceð that of the young daughter of Jewish parents who had survived the Holocaust, and then that of the mother of a child with a severe cognitive disabilityð she shows that these ties are ambiguous. First, we all want to be normal, recognized as such by others, and abnormality seems to be a barrier to a good life; second, no one wants to be loved simply for being normal, but rather as a unique being. In this way, normality appears as the backdrop against which everyone creates themselves as individuals with their own personality, and it is recognition that allows a good life. Yet, disabilityð especially when severeð places the individual in abnormality and raises questions as to his or

[1] Initially, we received 47 proposed abstracts in response to the call for articles. This large number reflects the current interest in this topic and its vitality.

her ability to have a good life. To hold this philosophic discussion (make a good life possible for these people), E. Kittay offers to re-examine the notion of normality. She highlights various possible paths to redefine it, insisting not on rational capacities (that some heavily disabled people do not control) but rather on emotional capacities such as joy or pleasure (that can be shared by everyone). E. Kittay then invites us to reconsider the criteria for a good life, basing them not on the ability to do but also and above all on peopleôs capacity to be in relationships.

In her commentary, Marie Garrau situates E. Kittayôs reflections in her philosophical trajectory. She explains how E. Kittay renews thinking on care and criticism of the ethics of justice based on her personal experience as the mother of a child with a severe cognitive disability. This personal situation led E. Kittay to insist on extreme dependency and explore how this extreme dependency forces us to transform our views of justice and equality. Indeed, for E. Kittay, the moral equality between human beings lies in the fact that each of us, when we are born, receives (or should receive) care from others, their love or concern. Babiesô vulnerability and total dependency, shared by all, cause specific moral and social obligations: we should all receive the care we need. Justice then flows from a twofold condition: equality of access to care and societyôs support of carers. Finally, M. Garrau explains how E. Kittayôs philosophical reflectionsð integrating her unique experienceð is in and of itself part of her care for her daughter; and this care is both indirect, because through her thinking E. Kittay works to transform our values, and direct because this reflection makes her attentive to the complexity of her daughterôs situation.

In the third article, Maks Banens and Anne Marcellini examine the meeting between the ethics of care and disability by looking at male carers (husband, father and to a lesser extent brother) of people with disabilities. Starting from a qualitative survey of six situations, they analyze if and how the fact of being a man changes day-to-day care work and, inversely,

if and how care work modifies traditional gender roles. They show that disability generates stronger interdependency between family members and that male spouses are caught in ñconsented dependencyò that paradoxically places them in a traditional masculine role of protector, a role that they did not necessarily play before. The authors show that, when done by men, care work does not necessarily or unequivocally transform the roles traditionally assigned by gender.

The following two articles, one by Antoine Hennion and Pierre Vidal-Naquet, and one by Delphine Moreau and Christian Laval, echo each other. They also look at day-to-day care work, this time done not by family but by professionals. Based on a few concrete aid situations that they analyze in minute detail, these two articles question the tensionð carried by the debate between the ethics of care and disability studiesð between concern for the other and promotion of his or her autonomy, between the responsibility of the provider and his or her desire to protect the recipient, and the care recipientôs capacity to decide. A. Hennion and P. Vidal-Naquet thus ask if constraint is compatible with care. Examining home aid situations, they show that constraint, far from absent in care work, is always present, and that it is linked to body resistance or resistance from people and the need to ñprotect people despite themselves.ò How care work is organized, the way in which peopleð aiders and aidedð are involved in the relationship, contributes to constraint in different forms, which makes it perceptible (visible) or imperceptible (invisible); peopleð aiders and aidedð try to move this constraint to the background, as a ñmasteredò and thereby acceptable constraint, but do not always manage to do so. This difficulty raises questions, doubts and uncertainties about what is good to do to help someone. Hence the authorsô proposal that care be though not only as concern but as ñworryò, as a necessary questioning of care practices in real situations.

In their article, D. Moreau and C. Laval raise a very similar question: to what point should one not decide for another person? The article is based on an ethnography of the

ñHousing Firstò program that consists of offering housing to homeless people with serious psychiatric conditions, and organizing their support by a multidisciplinary team in a ñre-establishmentò process. This process relies on the capacity of people to get better by defining for themselves what is helpful and meaningful for them. Based on this program, the authors analyze the place of the aided person in the care relationship and in the definition of good care. They show similar tensions as those analyzed by A. Hennion and P. Vidal-Naquet, between the need to let people decide for themselves and the need to protect them. These tensions raise questions for professional teams about assessing the severity of the situation and the appropriate mode of intervention. These questions manifest stronger or weaker worry in different forms and trigger the shift from care based on individualsô choices or at least a negotiation with them to care based on professional assessments. D. Moreau and C. Laval conclude their article by suggesting that this attempt to set up co-elaborated care seen in this program contains another tension, evoked by E. Kittay, between pre-defined normality and work on this normality, between norms recognized by stakeholders and the shift toward new norms of life and being.

The next article, written by Sarah Keyes, Sarah Webber and Kevin Beveridge, also addresses the tensions inherent in the care relationship and how this care relationship can lead not to subjugating but to empowering people. Rather than opposing the ethics of care and disability studies, the authors show that it is possible to combine their contributions to analyze how, in the aid relationship and therefore in some way based on a dependency relationship, people are made able to decide or do by themselves and in this way recover independence. After analyzing this question from the theoretical standpoint, the authors examine the question in practice: how can aid services be organized to make this combination concrete? Their response is based on two qualitative surveys in two aid services and a workshop that brought together researchers and field actors in Great Britain to discuss the challenges of this

combination of care and empowerment and how to organizeð concretelyð the services and relationships between recipients and professionals. The article thus discusses the theoretical and practical contributions of the notion of relational autonomy.

Finally, the last article is a research paper written by Jean-Luc Charlot. He presents the set up of a collective system to respond to the care needs of people with disabilities. It is the *Tiõ Hameau* scheme: people with disabilities each rent an apartment in accessible housing units and, by pooling their compensation allowances, provide themselves with 24-hour-a-day human aid. J.-L. Charlotôs description of this system extends the previous reflections and opens broader questions about the notion of ñsocial careò (Daly & Lewis, 1998; Martin, 2008) [2] and the political and institutional dimensions of care.

In this way, through the range of articles published in this first special issue, readers will find an examination of ñgood careò and ñgood autonomyò to preserve. This crosscutting issue calls for, in varied organizational contexts in France and abroad, continued investigation into the link between ethical issues and policy and social intervention frameworks at different scales. In this issue, the reflections mainly focus on the ñmicroò dimension of care, how care is distributed and defined in the family or in the local community. The articles published in the next issue (forthcoming, first quarter of 2016) will more explicitly address the social and collective dimensions of care and its policy stakes (in the sense of an examination of the organization and composition of society). The point of convergence between the two issues is, ultimately, the question raised by E. Kittay regarding the definition of normality and therefore how this normality is relationally defined and can therefore be modified in concrete situations in function of the qualities and capacities of each person, the type of aid provided, etc.

[2] During the call for articles, we did not, to our regret, receive articles explicitly exploring public policies on care, that is to say the dovetailing of day-to-day care practices and relationships with social policy and the role of the State (the notion of social care).

Bibliography

Albrecht, G. L., Ravaud, Jean-François, & Stiker, Henri-Jacques. (2001). L'émergence des *disability studies*: état des lieux et perspectives. Sciences Sociales et Santé, 19(4), 43-71.

Albrecht, G. L., Seelman, K. D., & Bury, M. (2001). Introduction: The Formation of Disability Studies. In G. L. Albrecht, K. D. Seelman, & M. Bury (Eds.), Handbook of Disability Studies (pp. 1-8). Thousand Oaks, London, New delhi: Sage.

Anspach, R. (1979). From stigma to identity politics: Political activism among the physically disabled and former mental patients. Social Science & Medicine, 13A, 765-773.

Barnes, C. (1999). Disability Studies: new or not so new directions? Disability and Society, 14(4), 577-580.

Beckett, C. (2007). Women, disability, care: Good neighbours or uneasy bedfellows? Critical Social Policy, 27(3), 360-380.

Daly, M., & Lewis, J. . (1998). Conceptualising Social Care in the Context of Welfare State Restructuring. In J. Lewis (Ed.), Gender, Social care and Welfare State Restructuring in Europe (pp. 1-24). Aldershot: Ashgate.

Fine, M., & Glendinning, C. (2005). Dependence, independence or inter-dependence? Revisiting the concepts of ócareô and ódependencyô. Ageing & Society, 25(04), 601-621.

Finkelstein, V. (1998). Re-thinking care in a society providing equal opportunities for all. Discussion Paper prepared for the World Health Organisation. Milton Keynes: Open University. Retrieved May 2015, from http://disability-studies.leeds.ac.uk/files/library/finkelstein-finkelstein2.pdf

Garrau, M., & Le Goff, A. (Eds.). (2012). Politiser le care , Perspectives sociologiques et philosophiques. Lormont: Le Bord De L'eau.

Gilligan, C. (1982). In a Different Voice. Psychological Theory and Women's Development. Cambridge: Harvard University Press.

Glenn, N.E. . (2009). Le travail forcé : citoyenneté, obligation statutaire et assignation des femmes au care. In P. Molinier, S. Laugier, & P. Paperman (Eds.), Quêst-ce que lœéthique du care ? (pp. 113-131). Paris: Payot.

Hughes, B., Mckie, L., Hopkins, D., & Watson, N. (2005). Love's labours Lost? Feminism, the disabled people's movement and an ethic of care. Sociology, 39(2), 259-275.

Keith, L. (1992). Who Cares Wins? Women, caring and disability. Disability & Society, 7(2), 167-175.

Kittay, E. F. (1999). Love's Labor: Essays on Women, Equality, and Dependency. New York: Routledge.

Kittay, E., & Feder, E.F. (2002). The subject of care : feminist perspectives on dependency. Lanham: Rowman & Littlefield Publishers.

Kröger, T. (2009). Care research and disability studies : Nothing in common ? Critical Social Policy, 29(3), 398-420.

Longmore, P. K. (1985). A Note on Language and the Social Identity of Disabled People. American behavioral Scientist, 28(3), 419-423.

Mackenzie, C., & Stoljar, N. (Eds.). (2000). Relational Autonomy: Feminist Perspectives on Automony, Agency, and the Social Self. New York: Oxford University Press.

Martin, C. (2008). Qu'est-ce que le social care ? Une revue de questions. Revue Française de Socio-Économie(2), 27-42.

Mol, A., Moser, I., & Pols, J. (Eds.). (2010). Care in Practice. On tinkering in clinics, homes and farms. Bielefeld: Transcript.

Molinier, P. (2013). Le travail du care. Paris: La Dispute.

Morris, J. (1991). Pride Against Prejudice: A Personal Politics of Disability. London Women's Press.

Morris, J. (1997). Care of Empowerment? A Disability Rights Perspective. Social Policy & Administration, 31(1), 54-60.

Oliver, M. (1990). The politics of disablement. London: Macmillan.

Paperman, P. (2013). Care et sentiments. Paris: PUF.

Paperman, P., & Laugier, S. (Eds.). (2006). Le souci des autres. Éthique et politique du Care. Paris: EHESS.

Pols, J. (2004). Good care. Enacting a complex ideal in long-term psychiatry. Trimbos-instituut, Utrecht.

Shakespeare, T. (1993). Disabled People's self-organisation: a new social movement ? Disability, Handicap & Society, 8(3), 249-264.

Shakespeare, T. (2000). The Social Relations of Care. In G. Lewis, S. Gewirtz, & J. Clarke (Eds.), Rethinking Social Policy (pp. 52-65). London-Thousand Oaks, The Open University: Sage

Shakespeare, T. (2006). Disability rights and wrongs. New York: Routledge.

Silvers, A. (1995). Reconciling Equality to Difference: Caring (F)or Justice For People With Disabilities. Hypatia, 10(1), 30-55.

Thomas, C. (1999). Female forms: experiencing and understanding disability. Buckingham ; Philadelphia, Pa: Open University Press.

Tronto, J. (1993). Moral Boundaries: A Political Argument for an Ethic of Care. New York: Routledge.

Tronto, J. (2009). Un monde vulnérable. Pour une politique du care (H. Maury, Trans.). Paris: La Découverte.

Watson, N., Mckie, L., Hughes, B., Hopkins, D., & Gregory, S. (2004). (Inter)Dependence, Needs and Care: the potential for disability and feminist theorists to develop an Emancipatory model. Sociology, 38(2), 331-350.

Williams, F. (2001). In and beyond New Labour: towards a new political ethics of care. Critical Social Policy, 21(4), 467-493.

Zola, I. K. (1989). Toward the Necessary Universalizing of a Disability Policy. The Milbank Quaterly, 67(Suppl 2 (2)), 401-428.